

What children on the autism spectrum have to 'say' about using high-tech voice output communication aids (VOCAs) in an educational setting

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Title

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Abstract

This paper focuses on accessing the experiences of three boys who are on the autism spectrum to identify what using a voice output communication aid (VOCA), within a classroom setting, means to them. The methods used to identify the boys' perspectives are described and evaluated. Establishing these through direct methods of engagement proved problematic but working with parents and school staff as 'expert guides' provided a rich insight into what using a VOCA appeared to mean to the boys. The findings suggest that using a computer based VOCA can be viewed by children with autism as a pleasurable and motivating activity. This technology also seems to offer the potential for a much broader developmental impact for these children than that currently recognised within the research literature.

Key words: autism spectrum, disability, AAC, VOCA, parents, voice.

Introduction

Traditionally disabled people and their families have been excluded from the research process: they have been researched on rather than with (Nind and Kellett, 2001; Barnes, 2003). When working with disabled children, Carpenter (1997) argues that researchers need to recognise that, 'the unique knowledge and understanding of parents is pivotal' (p.391). In the field of Augmentative and Alternative Communication (AAC) Goldbart and Marshall (2004) call for the perspectives of families of children who use AAC to be better understood by professionals so that these experiences might help to improve the nature and quality of service provision (Marshall and Goldbart, 2008). A vital element of this will be working with parents, and other family members, to access their understandings of how their children are responding to the use of AAC. The importance of including the voice of the child in the development of provision is highlighted within current legislation (Every Child Matters, (DfES, 2004a); The Children Act, (DfES 2004b)). However accessing the perspectives of children who use non traditional forms of communication is problematic (Morris, 2003; Beresford et al., 2004) and so some children still remain unheard. Those around the child may well be able to offer informative interpretations that can help researchers and service providers understand the child's experience from the perspective of an 'expert witness'.

This paper focuses on the experiences of three boys with autism, and the perspectives of their parents and school staff, to identify what using a high tech voice output communication aid (VOCA) within a classroom setting means to them. High tech communication aids provide the user with access to a large vocabulary, sentence building capacity and a voice, using portable hardware and communication software. The user moves through linked “dynamic display” word pages to find and assemble words, which the user may then “speak”, through the computer’s voice output. In this study low cost high tech aids were created by running voice output, communication software on school laptops.

There is no consensus about the value of communication technology for non verbal people with autism and they do not routinely access computer based VOCAs. Mirenda (2008) argues that non-verbal children, who are on the autism spectrum, are rarely provided with flexible, generative, AAC systems that can support long term language development because restrictive assumptions are made by researchers and professionals about the communication and learning potential of people with autism. Thus research in this field makes preponderant use of simple technology and conservative communication interventions that focus on requesting. In addition, research which has explored the attitudes and opinions of school age children who use communication aids, has often excluded children with autism (Clarke et al., 2001a,b) and we know little about these children’s views of AAC. In this research context, the current study sought to provide a rigorous evaluation of the use of computer based communication aids in an autism specific school, and explored stakeholder perspectives including those of the children. A more detailed account of how the project was constructed and the findings relating to the measured developments in language and communication will be reported elsewhere (Checkley, at al., 2009, in preparation). In this paper we discuss our attempt to give the children a voice within the evaluation of the intervention as we sought to explore what using a high tech VOCA in a classroom setting meant to them.

This project built on an earlier pilot study (Checkley, 2006) which had shown that by using dynamic screen, voice output software, the school laptops could become effective high tech VOCAs. The terms 'high tech VOCA' or 'high tech AAC' are used here to refer to computer based communication aids and 'low tech AAC' to mean non-electronic based materials. In the pilot study the high tech VOCAs appeared to be a promising communication support for children in curricular sessions; they were associated with increases in the children’s language and communication and with positive changes in staff perspectives of the children’s abilities.

Descriptions of disabled research participants are often presented as an unrelenting account of the 'can't do', a list of impairments without any celebration of achievement. We have tried here to give sufficient developmental information to enable the reader to evaluate the findings (Pennington, Marshall and Goldbart, 2007) but without presenting an impairment heavy account. Each of the boys had been given a diagnosis of autism through a medical model (Oliver, 1990) based process of assessment. We recognise many of the problems associated with the giving of labels (Gillman, Heyman and Swain, 2000; Hodge, 2005), and within the research team we had to negotiate different understandings of, and positions in relation to, these arguments and debates. The premise of this study is, in itself, an example of the tensions that surround labelling as it is based upon the belief that some children with autism have not been given the opportunity to experience the full potential of communication aids because of the low expectations that some professionals have of people with that label (Mirenda, 2008). However we choose to use the label of autism here because it feels necessary to 'claim' these children as having 'autism' if we are to challenge some of the assumptions made about other children who share this diagnosis.

The parents and staff were fully informed as to the nature of the study and the intended outcomes in terms of the publication of the findings. The parents consented on behalf of their children. The names of participants used in the paper are pseudonyms.

The participants.

Three boys were chosen to participate in the study. The gender balance for pupils within the school is 12:1. Gender difference in the use of VOCAs was not a focus of research in this particular study, although this would be valuable to look at in the future. Within this study it was three boys who best met the selection criteria. The boys were Cameron age 12:3, Daniel age 11:10 and Simon age 11:6. Each boy had attended the school from age 3:0. All the boys attended different classes. The three boys were selected for the following reasons: 1) they had shown interest and sustained attention in the use of computer based dynamic display vocabulary pages within individual activities. 2) They had sufficient attention control to move their attention between an adult led activity and a computer screen. 3) They had shown the capacity to use a visual vocabulary that exceeded their spoken vocabulary. 4) None of the students had a personal dedicated communication aid and none had been involved in AAC research prior to the research reported here.

All the boys had experience of using low tech AAC systems including “picture exchange”, through which requests are communicated by giving photos, pictures or symbols of desired items to an adult. The boys also had between 4 and 7 months previous experience of using high tech AAC in a weekly AAC communication group before the commencement of the research. This preliminary AAC group took an exploratory form and the participant boys were gradually recruited to join it. A stable staff structure, personalised computers and formal content were introduced to the group at the start of the research project.

All the boys experienced severe difficulty with using and understanding language. They used speech as their main mode of communication but their spontaneous speech was normally single words. The boys’ language was profiled using their current annual education review report, the British Picture Vocabulary Scale (BPVS II) (Dunn et al, 1997) and the Derbyshire Language Scheme Assessment (Knowles and Masidlover 1982). All 3 boys scored below the minimum standardised BPVS score for their age, reflecting the severe difficulties that understanding spoken vocabulary presents them with.

The parents who participated were Cameron's mother, Jane; Daniel's mother Sue and his father Ben; Simon's mother Sarah and his father, Phil.

School staff members were also recruited to the project. The boys’ 3 class teachers participated along with a dedicated staff member from each class team, who acted as the boy’s “communication partner” throughout the research period.

The project

The project ran during term time from September 2008 - April 2009, for 26 weeks. The research evaluated an AAC intervention which consisted of the following five elements; 1) each boy was provided with an individual computer based VOCA. These were created on

school laptops by running Ingfield Dynamic Vocabularies developed by Sally Connor and Janet Larcher, with Grid 2 communication software by Sensory Software International Ltd. These were personalised to make them as relevant, motivating and meaningful as possible to each child. Sample word pages are displayed in fig 1 (please insert here). 2) When using their aid, the boys had the consistent support of their communication partner, who facilitated the child's use of it. Partners took part in an introductory training session and practised partnership skills, with the support of the speech and language therapist, during the AAC group. Communication partners used a relaxed, encouraging approach, which affirmed and accepted all the boys attempts to communicate and they used modelling to support and extend the boys' VOCA responses. 3) Throughout the 26 week project, the boys and their partners practised using the VOCA in a weekly skill development group facilitated by the speech and language therapist (the AAC group). The group included periods of 'free choice' time when the children could continue to use their VOCAs if they chose to do so, alongside their communication partners. 4) Each boy used his VOCA in a weekly curricular lesson with the support of his communication partner for 12 weeks. Lesson activities were planned to promote communication, and relevant VOCA word screens were created for each lesson. 5) The staff team comprising participant staff and the speech and language therapist, informally and periodically discussed the children's achievements and challenges to inform on-going intervention planning, as part of the project management.

The VOCA was only available in school as the boys do not currently have access to this technology at home.

The next section of this paper will identify the principles that guided how the researchers accessed the children's perspectives on using the VOCA before presenting the children's views.

Accessing children's voices

The importance of gathering the child's perspective on what is happening to him/her in all areas of her/his life is increasingly being recognized (Every Child Matters, (DfES, 2004); The Children Act, (DfES 2004)). Kelly (2007) notes that historically in the area of research into disabled childhood, methodology has focused on using quantitative measurements. These may be taken for example through evaluation of interventions based on pre- and post-intervention performance demonstrated through testing. However, these methods only identify the impact of the intervention on the child's skill performance: they do not offer any insight as to what the intervention means to the child. The child's experience of an intervention is only usually included by researchers when children are sufficiently verbally articulate and 'able' to contribute to the research through interview.

The researchers in the current study adhere to a theory of the sociology of childhood (Davis, 1998) which argues that all children are social agents with their own perspectives and agenda, and that these perspectives are equal in value to the adult perspective. In this study, however, it was more complex because the adult perspective had a dual role: to report on how useful staff and parents thought the VOCAs were but also to advocate for the child's perspective. It is this latter role that is the focus of this paper. In our experience parents of, and the staff who work with, children who use non conventional forms of communication are often expert in

recognising, valuing and interpreting, a child's own understandings of his/her experiences. It has long been established within the fields of learning difficulties and autism that communication and behaviour are intimately related and intertwined (Clements and Zarkowska, 2000; Whitaker et al., 2001). The child's behaviour is seen in itself as communicative acts and parents and school staff are frequently better placed than external researchers to interpret these. We accept that the interpretations of children's behaviour given by parents and staff might differ significantly from the child's actual perspective and we are not suggesting that parents and staff will always be an accurate voice of the child. However they are likely to be a better informed and more practised interpreter of behaviour than a researcher who has had only a minimum of contact with the child. We concluded that the way in which a child was perceived by their parents, communication partner and other staff members to be using the VOCA in this study would be a useful indication of the child's attitude and mood whilst working with it.

Methodology

The current study drew on the growing body of literature that describes methods by which researchers have attempted to uncover the perspectives of children who do not use verbal communication. This literature identifies the importance of using the child's existing communication style in order to uncover what her/his experience is of his/her environments. The two main approaches employed by researchers are 1) the use of visual communication activities, such as pictures and symbols, to enable communication (Kelly, 2007) and choice making (Sigafos et al., 2005) including observation and interpretation of the child's behaviour especially in situations of free choice. 2) Parents and others who know the child well can become co-researchers, acting as expert guides to a child's system of being in the world. Hodge and Runswick-Cole (2008) argue that professionals who recognise the value of these parental contributions are likely to be 'trusted and well received' (p.645) by parents; thereby enabling more effective working partnerships to be established. Morris (2003) also recommends consulting with expert witnesses, suggesting that researchers access the views of more than one advocate for the child; thereby protecting against only one parent or staff member being assumed to be a full and accurate voice for the child.

In this current study the intention was to employ a combination of these approaches in order to gain as much information as possible about what the child's experience of using the VOCA might be. The data gathered throughout the study and which informs an understanding of the voice of the child was, therefore, drawn from several sources.

Sources of data

- The children were introduced to a self expression page on their VOCAs which included "I like" and "don't like" symbols allowing them to express a 'like/dislike' response (figure 2). For 4 weeks in the AAC group, they practised using these in an activity routine to respond to various items and experiences where staff considered their preferences were known, including video characters, websites, outdoor play equipment and foods such as garlic. In the following 3 group sessions, opportunities to use the symbols to express a response to the VOCA, were included. These were elicited for example, after watching a video of the AAC group and after viewing a slide of their software.

- Observations from free choice, child-led tutorial settings where the children worked individually with their communication partners and were free to choose access to their VOCA.
- Observations from semi-structured diary sheets completed by all the participating staff which recorded the boys' behaviours and communication during the literacy and AAC group lessons. Their records also included the free choice periods within the AAC group sessions.
- Information gathered from an analysis of the parent interviews and which reflected an understanding of the child's perspective.

The parent interviews

A member of the research team carried out one face to face interview per family wherever the parents felt was best suited to them. Interviews lasted for approximately one hour and the questions were presented to the parents in advance of the interview in case they wanted to have considered their responses beforehand. The interview questions were kept open, e.g. 'how do you feel he is getting on with the VOCA?' and 'have you noticed any changes in him since he has been using it?' The aim of the interviews was to identify what the parents saw as the benefits, if any, and the drawbacks, if any, of their child using a VOCA, any impacts on their child's development and their aims and aspirations in relation to their child's communication development. Opportunity was also provided within the interview for parents to ask any questions about the project. The school has a long tradition of working in close partnership with parents and it is hoped that those taking part in the study felt that they could give an open and critical account. We tried always to emphasise that we did not have a vested interest in a pro VOCA result: we just wanted to evaluate the potential value of the technology to children with autism.

The transcription of the interviews was shared by a university administrator and the member of the research team who conducted the interviews. The data was then analysed by another member of the research team, who was experienced with qualitative analysis, to identify what Goulding (1999) refers to as units of meaning: statements that seem to capture the essence of the experience for the participant. These units of meaning were then checked with the interviewer to evaluate how well these corresponded with her understanding of the parents' experiences, as described within the interviews. Where there were any differences in interpretation of the data the transcripts were then revisited for clarification. The units were then presented for discussion by all the research team.

When we initiated the project we anticipated, as a team, that the parents would want to talk about what they thought about the value of VOCAs but in fact, for most of the interview, they focused on what they thought using the VOCA meant or might mean to their child. It is this data that we are drawing on within this paper. Excerpts from the transcripts are given to identify the specific data that underpin our interpretations of the children's experiences.

How the children experienced using their VOCA

In his use of like and dislike VOCA symbols on the self expression page in the AAC group, Daniel demonstrated reliable understanding and use of these cells during the 4 preparation sessions. His use was consistent with his communication partner's knowledge of his interests

and preferences and he also confirmed some responses by adding comic gesture, for example pretending to faint when he smelt garlic. The complexity of trying to clarify perspectives, when adult and child use different forms of communication however, is illustrated by the fact that Daniel gave inconsistent responses when asked about the VOCA. His use of the dislike symbol confused his partner, who interpreted his behaviour as liking the VOCA; Daniel's behaviour towards the VOCA and his use of the symbol seemed to be in conflict. Other factors may have determined his response. For example, perhaps Daniel was referring to the specific word screen on display at that point in time rather than to the VOCA overall; his response may have reflected the way the choice was presented rather than what he really felt about his VOCA. Cameron and Simon were unable to use the like and dislike symbols, in the way that we presented them here, consistently in these activities and so we felt again that this method did not provide a reliable insight into their perspectives on the VOCAs.

In the tutorial and free choice situations Simon was recorded to have selected use of the VOCA in 80% of the sessions, Cameron was recorded to have selected it in 90 % of the sessions and Daniel in 93% of the sessions. This suggests that the boys favoured using the VOCAs. The diaries record that the boys chose to use their VOCAs for activities including book sharing, playing a game, looking at a favourite screen and making a personal interest page.

While we were willing to accept a dislike of the VOCA if we considered this to reflect accurately what the boys felt we were not confident that the like/dislike method enabled us to capture the boys' perspectives accurately. The observations of free choice seemed more reliable but were limited in what they could reveal about the quality of the boys' experiences of using a VOCA. For this we turned to the 'expert interpretations' of the children's behaviour by parents and staff. These accounts are presented below in relation to each child individually. We are making no attempt here to suggest universal themes for how children with autism might experience a computer based VOCA: there may be similarities between these children in how they engaged with this technology but we consider that each child's experience will be unique (Hodge, 2008). Like Mirenda (2008), what we do challenge, however, are any assumptions that children with autism can only have a limited range of use for communication aids.

Claims made about the children's experience are supported here by quotes from parents or staff to make it transparent how we have interpreted the data. This can make the reading of experience cumbersome at times but we feel that it is important to allow the reader to evaluate the quality of the evidence for him/herself (Kvale, 1996).

Cameron's experience

The school staff felt that Cameron enjoyed the VOCA, using it a way that appeared 'engaged' and 'interested' ; he 'explores' it. Cameron used the VOCA to extend the interactions that he would normally have with staff:

'He went straight to Grid 2 pages and explored the pages with interest. We were able to have a conversation about feelings'.

His communication partner noted increased 'self expression', 'independence' and 'self-confidence' and described Cameron as being 'very focused' with 'sustained interest' in his use of the VOCA.

Staff also felt that Cameron experienced the VOCA as calming:

'He remained calm throughout the session and I was sure it was down to the laptop...'

Cameron's mother, Jane, seemed to see the VOCA as just another aspect of computer use. She reported that Cameron enjoys using computers and is confident and positive with operating them. She felt that these fit with his learning style:

'...I don't think he has ever had a bad AAC session. He can totally relate to computers, because they are not a person probably, and he's very comfortable with screens'.

Like the staff, Jane also feels that Cameron finds visual systems of communication calming:

'...it really helps to calm him down, it helps him to know what's what and where's where...'
(Jane).

At home Cameron has decided for himself to use a digital camera to record and replay his experiences on a computer. This material can remain on the computer for as long as Cameron wants it; it remains accessible and can be referred to as often as required:

'...he can refer back to it any time he is in the mood' (Jane).

Jane feels that this activity provides Cameron with a sense of ownership and self motivation:

'It's his own personal project as well ...it's all his idea...'

It is also an activity that can be shared within the family:

'...I looked up trampolining for him in the dictionary because it's a huge word and he copied it quite happily' (Jane).

The computer feels like a support for Cameron, a site where he can practise emerging skills which he can then transfer to real life settings:

'...then he can do it independently' (Jane).

The computer based form of the VOCA enables Cameron to blend in: it helps him to avoid being 'othered', being positioned as different because of his impairment (Traustadóttir, 2001):

'...it's not something that marks you as being different' (Jane).

Cameron seems to find that the VOCA encourages his speech rather than acting as a substitute for it:

'I don't know if it is anything to do with the laptops but he has spontaneously described things recently, which has amazed me and been fantastic' (Jane).

The VOCA seems to be helping Cameron to remember words at home even when he does not have access to the technology:

'...so maybe he's remembering words better than he has before' (Jane).

Jane identifies some of the difficulties that Cameron encounters when trying to communicate and she hopes that over time the VOCA will help him with these. Although Cameron is highly motivated to communicate about things that interest him, his spoken language is often difficult for others to understand. Not being able to understand Cameron can then lead to others not realising the extent of his capabilities:

'...(at the) outreach club ---they have only just recognized how large his vocabulary really is. I really think they underestimated him to an extent that I was quite shocked....I am the only person that realises, other than the people at school....he does know and has a great understanding of what you say to him...' (Jane).

Cameron found that his levels of engagement with activities generally varied depending on his health. Jane reported that tooth pain, depression, epilepsy, response to medication and a lack of access to exercise in the winter months all affected his levels of communication. How much Cameron communicated also depended on to what extent he felt expected to. If he could work things out without having to communicate then Cameron seemed to accept this:

'He's quite used to tailor made situations, be it lessons or clubs, whatever, that he can fall into or out of as he pleases. He isn't challenged to ask...' (Jane).

Daniel's experience

The school staff note that Daniel seemed to view the experience of using the VOCA really positively:

'He definitely enjoys using the VOCA, he uses it with no hesitation or prompting'.

They felt that in some of the VOCA sessions Daniel was: '... particularly focused and communicative throughout'.

Daniel appeared to find that using the VOCA 'helped to calm him...' and enabled him to play a greater role within the classroom session. Through doing so Daniel could demonstrate his capabilities:

'I feel he participated more throughout the session. Having the VOCA allowed him to be more independent and helped him to access all activities to his full potential'.

Daniel experienced the VOCA as a means to express his personality which led to others having better understandings of him as a person:

'What I loved about the session was using the VOCA brought out Daniel's sense of humour... he's a cheeky joker of a child'.

Experiencing this success gave Daniel confidence and enabled him to assert himself on his environment:

'Throughout I have seen his confidence build. It is lovely to see'. 'Increased level of confidence vocally, shouting out answers'.

Daniel's mother, Sue, also feels that he is experiencing greater confidence. She observes that access to the VOCA makes Daniel feel less pressured to talk:

'... it takes all the pressure off his speech and taking pressure off the speech enables the speech'.

As a result Daniel seems to be extending his speech:

'I agree that he's certainly increased his phrases significantly in the last 6 months or so' (Ben, Daniel's father)

and using speech in more complex and different ways:

'...he is using it (speech) a lot more...he seems to be asking for things and commenting on things, calling for me, which he never did ...he's using more words...it does seem to coincide (with using the VOCA)' (Sue).

Daniel's parents related the use of the VOCA to his enjoyment of computers generally:

'He loves them, absolutely loves them, so it (VOCA) builds into all the things he likes' (Sue).

Computers are familiar and safe:

'...we have laptops at home, so he gets pleasure from it, so it's not a sort of threatening medium for him' (Sue).

They can be a site of family sharing:

'...things of interest he was showing us: the German Playmobil website...' (Sue).

For Daniel the accessibility of the technology is important:

'It's always about having it there that enables him to use speech' (Sue).

Daniel finds that the VOCA helps him with word recall:

'...he really struggled with words and that was his biggest problem' (Sue)

and with planning out and rehearsing what he wants to say:

'It feels like because there's a cue there, he can see it on the computer and he stops struggling and he can find it...he can see the format and hear it and plan it...' (Sue).

Daniel appreciates the range and flexibility of a computer:

'I think that this is a really positive step on, giving him much more flexibility than the initial stuff that we had' (Sue).

Although Sue is unsure what she can attribute solely to the introduction of the VOCA, it seems to her that Daniel is experiencing the benefits of the VOCA at home as well as in school, even though he only has access to the VOCA within school. At home he is using his communication to a greater extent socially since the introduction of the VOCA, sharing experiences through commenting and using his language to change what happens around him:

'Asking for more things more competently... and he seems to be asking for things and commenting on things, calling for me, which he never did...he's using more words... he's just more interested in communication...He's more engaged'.

Ben feels that the VOCA is enabling Daniel to find life less frustrating and upsetting:

'He gets a lot less cross, he doesn't get as frustrated as he used to...'

Sue and Ben see the VOCA as developing Daniel's language to the extent that they are now more able to negotiate as a family:

'...you can explain things to him...you can negotiate which you couldn't before' (Sue).

Daniel's parents have seen video footage of him using the VOCA in school and in this they see a boy who is more confident and relaxed in school; he can now show his 'home self' there:

'They've shown us videos ...he's starting to grow more confident. ... he's much more the child we know at home at school now...' (Sue).

Simon's experience

The staff members' diaries record Simon being moderately engaged with the VOCA. However, a significant proportion of the sessions were classified as 'atypical' indicating a potential disruption to classroom learning that occurred because either the staffing in the group was different or some other feature had suddenly changed. Simon, who seems to rely on a high level of routine and predictability, is likely to find this extremely difficult to deal with:

'Simon pushed the VOCA away after only a few moments. Possibly due to changed room and partner'.

Simon did use the VOCA as a support for word recall:

'...(as a) word recall device. Points to the symbol then repeats verbally, with or without activating the cell'.

It was difficult for staff to gauge exactly what Simon made of the VOCA. Although he did not seem overly enthused with it he did engage with it to some extent. One staff diary account recalls that in one session he was:

'Very interested and was confident using it'.

Another staff diary entry reports that the VOCA seemed to help to distract him from an unsettled mood. These observations would seem to suggest that overall Simon perceived the VOCA positively; a conclusion that would seem to be supported by the fact that he chose to use it in most free choice sessions.

Simon's parents, Sarah and Phil, report that although he uses few spoken words Simon has developed, for himself, some effective communication strategies:

'You know its reading his body language a lot...his little squeaks...the certain pitch of a squeak means he's angry or whatever'. 'He doesn't really have a problem with asking for things, if he wants something he'll make it clear'.

They observe that these strategies work well with communication partners who know Simon well, but do not offer much help to Simon in his communications with those outside of this group. :

'Nobody knows the little things that he wants' (Phil).

Simon's parents feel that he enjoys communicating:

'...He likes a banter. There are certain things that I know when he says that I have to say that several times and he will repeat it...He's got a wicked sense of humour' (Sarah).

He seeks out communication, often selecting those whom he thinks are most likely to understand him:

'Even now he'll come to me rather than Phil because he thinks I will understand' (Sarah).

Although Simon does use a computer at home for some activities, such as watching video clips, his parents predict that Simon will be reluctant to surrender his own system of communicating to use the VOCA:

'...I don't think he's going to start going towards the computer (referring here to use of the VOCA) rather than talking ' (Sarah).

However, Sarah and Phil do think that the visual nature of the VOCA will play to Simon's strengths:

'He's very visual, very into PECS and symbols so if anything's going to work it's going to be this clicking on the symbols and finding words' (Sarah).

Simon's parents reported that it was hard for them to identify how he might feel about the VOCA as they had not received sufficient information about how he was responding to it. They did consider however that it had the potential to be something that Simon would find beneficial. His parents hope that he might come to appreciate how it could expand his world and make him less vulnerable because he could communicate his desires and opinions to a wider range of people:

'Nobody knows the little things that he wants. We understand...It (the VOCA) would give him a bigger world. We'd feel more comfortable with him being (left) with his cousin or a relation' (Phil).

The VOCA might help him with word retrieval:

'So with pictures if he wanted to find certain words it could be useful to him' (Sarah)

and enable him to let others know what he felt about situations:

'...with the facial expressions that he can click on...maybe he'd be able to express himself a bit more...' (Sarah).

This would then help with family negotiations:

'...if he learned some new words that could help us communicate with him or us explain something to him' (Sarah).

Simon's parents find that his levels of communication depend upon the state of his health and are affected by significant anxiety, compulsive behaviour and the medication used to help him manage these.

Discussion

It is recognised that the people who rely on communication aids are key sources of evidence for evaluating the effectiveness of these devices, but that their voices are often the hardest to hear (Blackstone, Williams & Wilkins 2007). In the field of autism and AAC, Miranda (2008) has argued that professional assumptions about the skills and potential of people with autism, have held back research, leading to a focus on simple and conservative AAC interventions. In

this study, it was important to us therefore to try and include the views of the participating boys in our evaluation of the impact of access to high tech VOCAs for children with autism.

We adopted a 'Mosaic Approach' (Clark and Moss, 2001, cited Beresford et al., 2004) that drew on a range of sources to help access the children's views; parent interviews, staff interviews, video analysis, observation, free choice and like/dislike options. All of the research team are experienced in working with children who are on the autism spectrum but we still found accessing the boys' views directly challenging and problematic. Our attempt to enable the boys to express a view using their VOCA, through the use of familiar "like" and "don't like" symbols illustrated some of the difficulties of communicating with AAC.

Communication breakdown occurred, because the boys and staff did not understand or use the key concepts in the same way. Like and don't like are also limited in what they can reveal of an experience. They do not allow for contextualising the comment: they do not permit an explanation such as, 'I like the VOCA generally because it enables me to have more control of my environment but I don't like this particular activity that we are doing with it'. Next time we would try, if appropriate for the participants, giving more extensive and concrete options such as those used by Rabiee, Sloper and Beresford (2005). For example asking a child to select statements that might apply such as, 'Callum wants his VOCA to ask for things that he needs' or 'Callum wants to use his VOCA at home'. The free choice paradigm revealed that the boys had some interest in using the computer VOCAs in self directing contexts and recorded their individualised use of the VOCA in this situation. These two tools did, therefore, give us some initial insights into their experience of using VOCAs; they illustrated communication breakdown and revealed the boys' autonomous interest in accessing their VOCAs but they did not go as far as we would have liked in revealing what using a VOCA meant to these boys.

Reflecting on one's own experience, being able to articulate this to another person and understanding the intention behind a question are all activities that challenge many people on the autism spectrum and make accessing children's understandings difficult for researchers. This has resulted in children with autism being marginalised from the research process. Whilst we appreciate the challenges for researchers and are frustrated ourselves that we were not able, in this study, to find more reliable ways of accessing the boys' meanings of their experiences we agree with Beresford et al (2004) that it is vital that researchers persist in their attempts to include children with autism, as far as is possible, in the research process.

In this study we found that it was the parent and staff contributions that enabled a rich insight into the boys' complex experiences. For example, parents and staff reflected on the boys' feelings as they used their VOCAs and their levels of interest in them. They considered their confidence and competence with both computers and VOCAs and their use of computer technology at home. They considered the boys' experiences of independence and ownership, their learning styles, and the power of VOCA access to calm the boys. They described the boys' communication strengths and difficulties and evaluated how the VOCA might relate to these. They also considered how the VOCA could enable their child to demonstrate in the school setting, the levels of personality and skills seen by the parents at home. Through these parent and staff reflections, distinct and individual profiles of the boys' VOCA experiences and responses emerged, in which the boys showed different levels of interest and patterns of response to VOCA use.

The availability of resources can also limit the choices of researchers. This was a small budget research project for which funds had been raised with the principal aim of evaluating

the impact of VOCA use on the language development of children with autism. The resources raised governed how much time could be given to the collection of data and for future studies we would know to allocate greater resourcing to this in the planning stage.

However, accessing the boys' understandings of their experience through those who know them best did not necessarily feel to us like 'second best' (Rabiee, Sloper and Beresford, 2005). Our analysis of the parent interviews and staff diaries suggests that these boys had a complex relationship with their VOCAs, which goes beyond its impact on their functional communication. This related to their existing skills and styles of communication, the perceptions of people in their environment, their level of enthusiasm for computer technology, their personality and their state of health and well being. For Daniel and Cameron this relationship was positive, but Simon had a more ambiguous response to the VOCA. Our analysis revealed that computers were commonly used at home by all the boys; this was familiar technology. In addition, the VOCA's visual mode matched the preferred learning style of the children. Using computer based VOCAs thus represented an extension of an area of confidence and competence for these boys; they were at ease with this technological level of communication aid.

Conclusion

Consulting with all users of high tech VOCAs, whatever their impairment, should be an essential element of planning for policy makers and service providers. In the area of AAC and autism where assumptions about children's potential are argued to have restricted the research agenda, we view the search for the child's voice as a priority. Researchers will need to be creative in how they access the full range of experience. Where it proves too challenging to enable AAC users to articulate their experiences and aspirations, through signing, picture or symbol use, then those who know the child well can be called upon as a support resource, as expert guides to understanding and advocating the child's perspective. However no one 'other' voice can safely be assumed to be that of the child (Komulainen, 2007). It is helpful therefore, within a mosaic approach, to consult a range of guides, some of whom will be more expert than others, to support the researcher with feeling his or her way through to the child's perspective. In doing so researchers will need to be mindful of achieving a balance between the desire to gather this data and the requirement to avoid placing unreasonable demands on parents and staff.

In this study we feel that the data collected through the staff diaries and through the parent interviews has been invaluable to us in providing 'expert' insight into how each of these children may have experienced using the VOCA. However, we still feel the need to reflect on our practices and look for ways in which we might have been able to access the boys' voices more directly. We are clearly not claiming 'best practice' here in terms of giving voice to the child, rather we are highlighting some of the challenges for researchers and describing how we responded to these. We feel that it is vital to maintain discussion and debate on how researchers attempt to engage children, who are experiencing very different ways of being in the world, in the research process.

In this study we have relied heavily on the 'expert witness' approach. What we have learned from this is that a high tech VOCA offers positive support for the development of children with autism. While we cannot attribute the reported changes in development strictly to the VOCA, as there are so many variables that affect children's learning, it would seem that high tech AAC can be experienced by children with autism as an engaging, meaningful and

accessible tool that encourages speech and communication. Using this technology may well suit some more than others and some children may take longer to recognise its potential but all of the children in this study seemed to benefit from it to some degree. Our analysis indicates that the boys had complex and individual perspectives on high tech VOCA and that they had different views on the value of using them. However, it suggests that the boys generally found a VOCA to be a portable, familiar, fun, flexible, everyday piece of equipment that fits with their visual and structured learning style. Most importantly this study indicates that the use of high tech AAC has a far greater potential for personal and developmental impact, for children on the autism spectrum, than is currently recognised in the research literature and the professional field. High tech AAC can provide much more than the satisfaction of needs and wants alone.

Figure 1: examples of word pages, showing a) master page b) a game page c) a personal interest page d) sentence practice page.

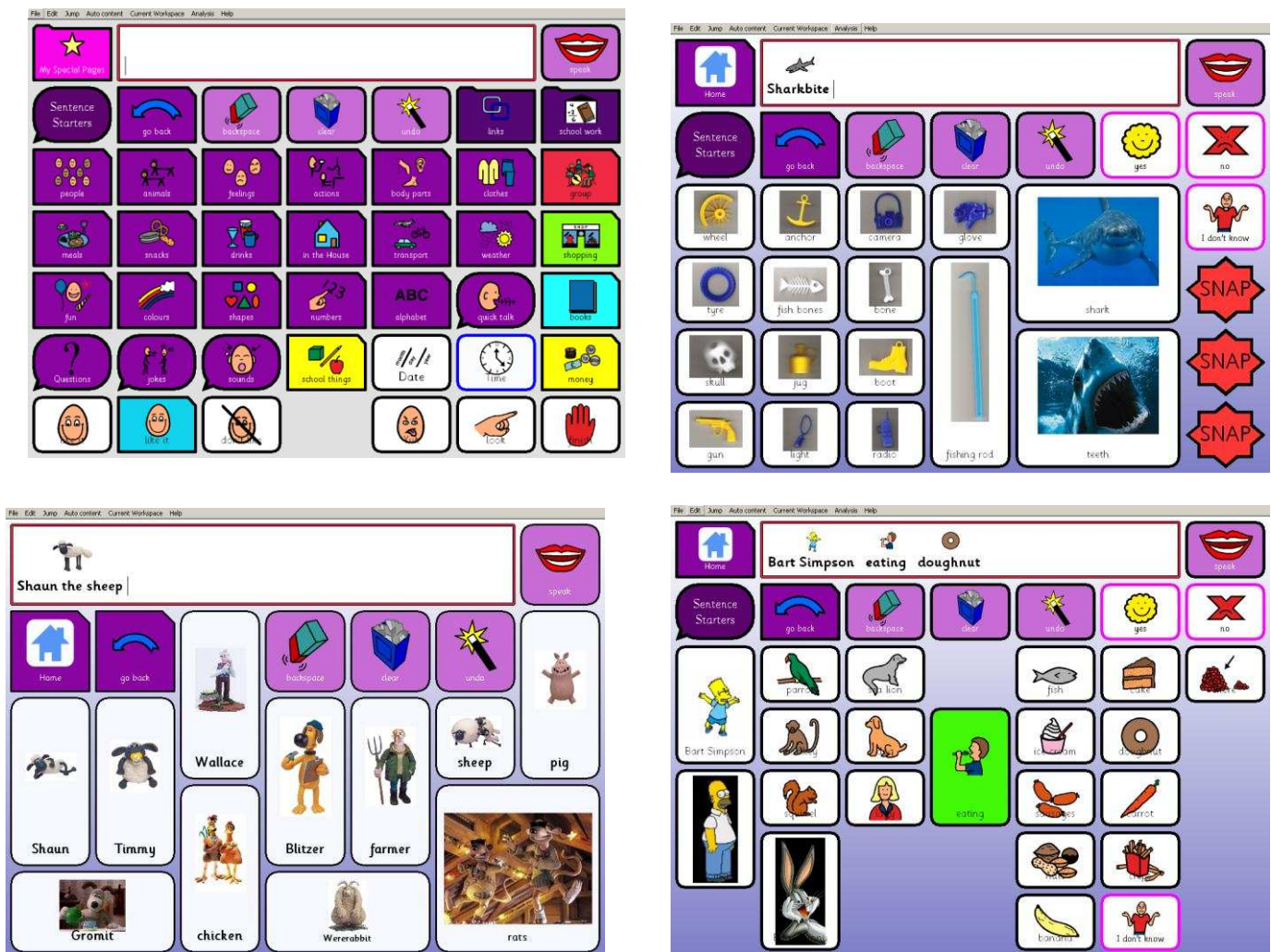
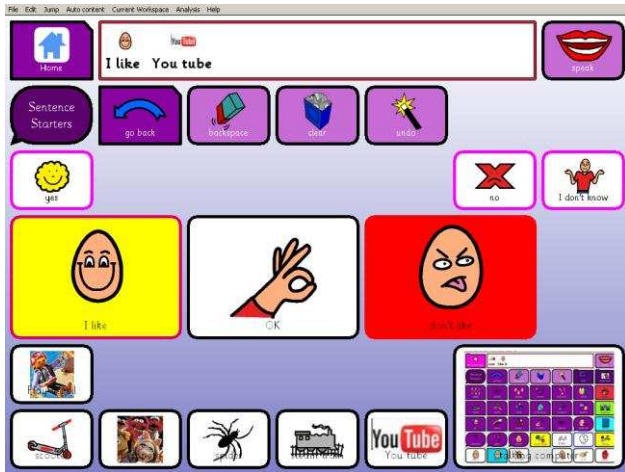


Figure 2: Example of self expression page, used to describe items in a slide display.



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